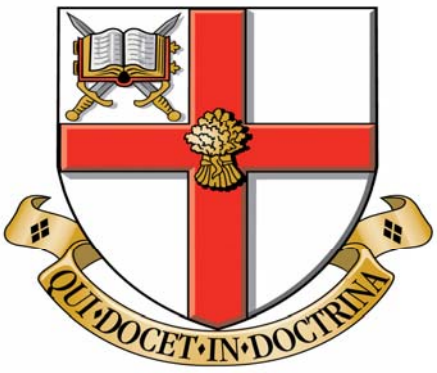

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Counsellor's experience of living with a child with a chronic illness

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Abstract

This qualitative research is an exploration of the subjective experience of being a parent of a child with a chronic illness and the personal meanings that are attributed to this phenomenon. The data was gathered from four practicing counsellors, using semi-structured interviews and analysed by Interpretative Phenomenological Analysis (IPA).

The aim of this study is not to propose any 'universal truths' about a parent's experience. However, this glimpse into their subjective experience provides valuable insight to what emotional and psychological factors have impacted them as a parent since the diagnosis of their child's illness.

From the point of view as a parent it raises some implications for an empathic understanding of how they feel as a mother, whilst looking at additional support at crisis points of their child's illness, including the diagnosis.

The primary findings were the emotive symptoms that parents experience categorised as: Shock, Loss, Fear, Anxiety & Stress, Helplessness, Sadness & Hurt, Denial, Disbelief, and Loneliness. There were a number of other challenges that parents face whilst being a parent of a child with a chronic illness, with reference to the emotional and psychological impact, along with how they have coped.

These findings can also support research in this area.

DECLARATION

“The work is original and has not been submitted previously in support of any qualification course.”

Signed: .....

Acknowledgements

I would like to acknowledge my son Ryan for allowing me to use him as inspiration for this research project and my other son Adam who remained a constant during difficult times. I would also like to thank my mum for all her support and the practical help that enabled me to complete this course and go on to do my dissertation; she remains my inspiration and my support in all things.

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Finally, I would like to acknowledge my partner Mark who is a very special person in my life; I met him at the beginning of the MA in Clinical Counselling course and he has remained a constant reminder that I was also a person amongst all the books.

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Chapter 1

Introduction

The aim of this qualitative study was to explore the subjective experience of being a parent of a child with a chronic illness and the personal meanings that are attributed to this phenomenon. In particular, I wanted to investigate what the emotional and physiological result is, of an extraordinarily stressful and potentially traumatic experience of having a child with a chronic illness and what impact this has had on my participants and if, or how it manifests itself.

The focus of this study emanated from my gradual awareness of the emotional and psychological impact that happened when my son was diagnosed at 10 days old. The diagnosis was a life-limiting, chronic illness and the prognosis involved spending many days, months and years in hospital whilst he was treated, and still does. It is an experience that has taken me on a journey that has been both painful and profound, and 17 years later, I still carry a sense of loss and grief. I have felt the profound effects of anxiety, fear and helplessness and I believe I still do, except I recognise now how this has and still does impact on my sense of self. The somatic sense of shock still permeates through my life, although it feels different as time has gone by, the experience has still affected how I see the world, and sadly, this doesn't leave me. I also recognise how my behaviour and life choices have followed on from the emotional and psychological impact of my experience.

My primary incentive for this study is my firm belief that it is only by asking people about their experience of being a parent of a child with a chronic illness that we are able to learn about the nature of this experience from the point of view of the parent. I wanted to interview counsellors as I feel they would be more robust for my interview

questions, through having had the personal development element in their training to be a counsellor, and they also have access to counselling supervision. Whilst also being motivated by my own experience, I want to give a voice to my participants, in what I feel is a misunderstood phenomena. This is also an area of concern from a wider context, as estimates and the prevalence of paediatric chronic illness have indicated that 31% of children under the age of 18 have a chronic illness, bringing the national total to 18 million (Melnyk, Feinstein, Moldenhouer & Small, 2001). A more recent figure has been estimated at more than one-tenth of children suffer from a chronic illness. This has a huge impact on our wider resources but it also shows how much has been placed on parents along with the responsibility to administer their child's everyday care (Dempsey, 2008). Shockingly, it has also been reported that mothers were likely to become neurotic, depressed, introverted, lack self-confidence and become generally more anxiety-ridden than fathers of chronically ill children. In particular they will experience the following emotional reactions: shock, confusion, numbness, denial, anger, anxiety, guilt, self blame, fear, helplessness, depression, as well as inner resentment toward the sick child, spouse, and other children (Rao, Pradhan & Shah, 2004).

To understand this phenomenon, I gave my research the title: 'Counsellors' experience of living with a child with a chronic illness'. Chronic illness is defined as a medically diagnosed ailment with duration of six months or longer, which shows little alterations or slow progression (Brown, 1993; Williams, Lorenzo, & Borja, 1993). For the purposes of my study, childhood chronic illness is identified as, but not limited to, asthma, cancer, cardiac disease, cerebral palsy, congenital disabilities, cystic fibrosis, epilepsy, gastrointestinal disorders, hematological disease, juvenile

rheumatoid arthritis, inflammatory bowel disease, nephrotic syndrome, renal failure, rheumatic disease, scoliosis, sickle cell disease, and spina bifida.

Aim

The aim of the study is to explore the experience of counsellors' whilst being a parent, and identify what emotional and psychological factors have impacted parents of children with a chronic illness, whilst also capturing what other areas that may emerge to help understand this phenomenon. By using the counsellors' experience of personal development, I hope to contribute a deeper understanding for analysis.

Rationale

Current studies I have researched have examined the potential impact of childhood chronic illness on parents, including the crisis points at which significant change has to occur in the parent's model and behaviour (Davis, 1998). Brown et al (2007) refers to how there is an undeniable impact that can be both positive and negative, indicating experiences of anxiety, depression, posttraumatic stress, hopelessness, and the feeling of loss. While Shudy and colleagues (2006) identified specific stressors and coping strategies that occur at diagnosis and during treatment, including symptoms that often mirror posttraumatic stress disorder (PTSD). Whilst taking an exploratory step, I hope this will be useful and informative to other counsellors and health professionals. It also has the potential to make a significant and necessary contribution to the evidence base for counselling and psychotherapy and lead to insights for further study (McLeod, 2010).

In order to achieve this I carried out a review of the relevant literature, which I provide a critical analysis of in Chapter 2. I am aware of limitations of this dissertation, so I

was mindful of not digressing into the other related subjects of; impact on siblings, family functioning and the fathers role, although this was explored during the interview it was more from an observational point of view whilst capturing how much impact had occurred. This is also a small-scale study and its data is limited, but it does show how this area could be developed and built on for further research. Most studies have investigated the impact of the child's chronic illness on mothers, assuming that fathers perceive the illness, react, and cope in a similar manner (Katz, 2002). Ultimately the illness affects the entire family, 'It is a whole family experience and how the ill child copes is dependent on how the entire family is supported' (Dempsey, 2008. P.19). I have included this aspect in a small amount of my research where I determined the material was of particular pertinence to this study, as this impact is evident throughout my literature research. There has been little qualitative research linked to the exploration of the pressures faced by parents, especially mothers. My study has only included the mother's perspective in relation to the emotional and psychological impact, whilst still hoping that my study will help towards a better understanding of a parent's experience. The review of literature suggests that chronic illness in children affects the psychological health of the parents, and active coping strategies are associated with fewer distress indices and thus if inculcated may improve the ability to bear the burden of the illness (Rao, Pradhan & Shah, 2004). I also hope to capture the attention of professionals who work with parents of child with a chronic illness within a variety of settings, as the review of literature also suggests professionals who work with families where a child is ill are familiar with the dynamics fueling the dyadic attachment between parent and ill child. There were feelings of guilt, helplessness, and the difficulty in reversing an established pattern of anticipatory mourning for the parent, along with the feelings of isolation from normal life, all played their part in the relationship (Walker, 1983). By

appreciating these wider implications, this can hopefully lead to more informed advice and support. After a thorough search of the literature available to me, the resulting body of knowledge helped shape my decisions about the information I wanted to investigate.

In Chapter 3, a qualitative approach has been adopted which allows the researcher to be more sensitive to the multiple interpretations that individuals may make of experiences in an attempt to gain some sense of meaning (Willig, 2001). Qualitative analysis is particularly effective with topics for which there is little previous research, and where there may be variables that are difficult to identify or they have not yet been identified (Morrow, 2007). I advertised to capture a sample of 4-6 participants that was a purposive homogenous group, and for whom the research question was specific and meaningful along with what would yield a clearer understanding of the phenomena and produce a small in number but 'information rich' narrative data (Patton, 1997). In formulating my interview questions (Appendix 13), I was clear that my aim for this study was to explore the lived experience of parents with a child with a chronic illness, rather than test a pre-defined hypothesis. My interview questions focused on what has had the biggest emotional and psychological impact on them as parents, and add a deeper awareness of this human experience rather than validate previous theory or findings (Elliott, Fischer and Rennie, 1999). My four participants were asked to give their accounts using semi-structured interviews. I analysed my participants transcribed interview data using the Interpretative Phenomenological Analysis (IPA) by following Smith, Flowers and Larkin (2012) guide. The steps I employed involved repeated reading of the transcripts and notes were made on descriptive and conceptual comments as they appeared in the transcripts. Within each transcript the notes were then condensed to produce emergent themes, when

this process had been completed on each transcript, themes were identified across the emergent themes, and groups of super-ordinate themes were created that led to master themes emerging (Appendix 15).

In Chapter 4, I offer a presentation of the outcomes with the findings. Chapter 5, I offer my discussion and finally a conclusion of these results as well as my recommendations and ideas for further research, in Chapter 6.

Chapter Two

Literature Review

The existing body of literature describes an undeniable impact, both positive and negative, of paediatric chronic illness on the family dynamics, adult dyadic relationships, finances and the emotional well being of patients, parents and siblings. While it is beyond the scope of this dissertation to review all published studies that relate to the family. This literature review focuses on the emotional and psychological impact on parents who have a child with a chronic illness, and contains references that are relevant to what these symptoms are and how they are presented.

Research Strategy.

The primary method used to retrieve relevant data was an electronic literature search of databases provided by the University of Chester, namely PsycINFO, CINAHL, PsycARTICLES, PsycBOOKS, SocINDEX, and the BACP website and Google, along with the books held at the university library and my own collection. The databases were searched using and focusing on the following keywords: chronic illness, illness, disability, children, families, relationships, impact, experience, living with, therapy, counselling, support and coping (Appendix 1). In order to take account of the differences between English and American spellings, as well as to include variant word endings (such as counselling; counsellor; therapy; therapist), I used truncation after the roots ‘counsel’ and ‘therapy’ in my searches. I also adopted the Boolean operators ‘and’ and ‘or’ to maximise efficiency and relevancy of my results.

Results from the literature search.

The search resulted in more academic articles and journals than books on the related subject. They were predominately focused at professionals in health care settings; a majority of these offered a variety of models and interventions that would assist them whilst supporting parents of child with a chronic illness, whilst focusing on how the families can adapt to their child's illness. I only found two books that were based on the personal journeys of the parent of a child with a chronic illness. Current studies found have examined the potential impact of childhood chronic illness on parents, including the crisis points at which significant change has to occur in the parent's model and behaviour (Davis, 1998). Although this clearly has implications that intervention, promotion and fostering change is needed for parents and the family. I decided that it was beyond the scope of this study to include the majority of this literature. However, I have utilised some of the crisis points & biopsychosocial aspects from this literature in this area where I deemed it useful to this study's aims. In general, the literature has delineated a myriad of stressors that parents experience; financial stress, role strains, separations, adjustment, interruptions in daily routines and plans for the future, and the uncertainty that is felt with regard to the child's prognosis. While Katz (2002), and Brown et al (2007) have identified specific stressors and coping strategies that occur at diagnosis and during treatment. I excluded articles relating specifically to how the family functions, family systems, and specific named illnesses and professional interventions, but following my interviews I returned to include some of this literature due to the themes that emerged from the participants' material, this was mainly with regards to when references that were made that emotional support is needed for parents at crisis points.

Given that this is a relatively new area of research the literature retrieved is dated

between 1990 and 2008 and the majority of the studies, articles, journals and books come from social science, paediatric and child psychology along with nursing journals. Eleven of the fifteen articles that my search identified were published in America. Only one was British and one each was from Australia, Canada and Finland. This confirms that there is a recognised need for counselling and psychotherapy research and also more from a British perspective (McLeod, 2010).

From the results of my search, I found 3 themes evolving from both the title and the abstracts. They featured models, approaches and exploring what happens when your child has a chronic illness. They went on to separate into a further 3 different areas around the child's illness, but all mainly focusing from a professional view point, and then only on the family as a whole unit, from a professional point of view and finally on to how the parent copes, which included interventions focusing on specific illnesses.

Literature available.

The search for qualitative literature that is specific to parents of a child with a chronic illness has been limited. The search resulted in papers predominantly focusing on a variety of recommended interventions and support mechanisms that is directed at the professional's role whilst advising how they can help the child adapt to their illness. Some case studies looked at interventions surrounding specific illnesses in the child and how they cope. This lack of evidence based, qualitative literature has been acknowledged by Rolland (1994) stating, 'to date there is less literature on family systems consultation and therapy approaches to chronic and life threatening illnesses' (p. 5). This lack of exploration into direct experiences and the emotional psychological effects of being a parent of a child with a chronic illness allowed

Rolland (1994) to be a prominent figure in my literature search and area of study, he also explored the biopsychosocial nature of ‘illness’ along with the dialectic between family members and the medical system. Whilst his books and journals are directed towards the health professionals who work in a variety of clinical settings, as an expert clinician, it was initially inspired by Rolland's own experience of the strains involved when his wife became seriously ill. Rolland’s book uses a framework that shows how the biopsychosocial demands of different illnesses create particular strains on the family, how the stages of an illness affect the family, how family legacies of loss and illness shape their coping responses, and how family belief systems play a crucial role in the ability to manage health and illness. On focusing on my subject area, I also found Dempsey (2008) who aptly named her book ‘Extreme parenting’ had written about her personal experience of parenting a child with a chronic illness. She has captured the emotional and psychological impact, which is the essence of what I was looking for in my qualitative study, and to which I have made several references. Although my findings have captured what health care professionals need as a reference point, these assumptions and suggestions also relate to my research area and represent what areas are available as support to parents whilst also validating what areas need addressing for future research.

Leahey & Wright (1984) state how their primary objective for their study is for the health care professionals that work with families with chronic illness, they refer to how they can assist the family adjusting and adapting to the child’s chronic illness but not necessarily to accepting it. Davis (1998) has offered a more sensitive approach, stating his aims are to help medical staff and carers relate to parents in ways that facilitate their adaption to their child’s illness. The essence of the help is communication, whilst exploring what difficulties are encountered in all aspects of

their lives, including the setting of goals, establishing problem-solving strategies and evaluating the effects on parents who's have a child with a chronic illness. Walker et al (1996) proposes that the primary medical care of the child rests with health care professionals, and that pediatric chronic illness necessitates that parents play the primary role in managing the medical care needs of the child. Adding that although the etiologies, symptoms, treatments, and prognoses vary significantly between different pediatric chronic illnesses, the resultant stressors on parents are very similar. While Morrison, Bromfield & Cameron (2003) refer to a model that presupposes that the chronic illness and/or disability of a child constitutes a trauma for the parents, whilst offering interventions that address the psychological dynamics of hope and reframing. It is obvious that these different viewpoints offer more assumptive literature than evidence based, and they lack the capacity to capture what it actually feels like to be that mother, parent, care giver or carer. This is where, I hope, my research is making its unique contribution in exploring the experience of those living with a child with a chronic illness.

Conversely, Kuehne (1989) refer to how raising a child with a chronic illness is a taxing, expensive, and often lonely experience for families (Glazer-Waldman et al, 1992). And in a more recent qualitative study Anderson & Davis (2011) state, how a chronically ill child is financially, emotionally, and physically demanding on the family system. Whilst further referring to how researchers in qualitative studies have identified a plethora of risks, stressors and needs of the families with a chronically ill child, there is also a scarceness of evidence-based interventions from a parent's perspective in the existing literature.

Furthermore, the literature that does indicate what stressors, impact or symptoms

that have been found in parents with a child with a chronic illness seem to be broad and general and seem to focus on a wider audience. Glazer-Waldman et al (1992) refer to how parents may experience feelings of confusion, uncertainty, loss of control, fear, anxiety, guilt, or anger, along with the family life being disrupted. These symptoms could include most acute or mild illnesses or similar groups. Hopia, Paavilainen, Stedt-Kurki (2005) offer similar symptoms, whilst adding how parents have to adapt to a nagging sense of uncertainty to their life being split between home and hospital, and to the constant changes in everyday life. Along with the stress, uncertainty, anxiety, hopelessness, guilt, fear and sorrow that are recurring emotions in all parents during the child's illness.

The emotional and psychological impact on parents who have a child with a chronic illness.

The reality is, the plethora of stressors that a parent of children with a chronic illness may experience, is vague and broad, and given that it is a new area of research the literature retrieved has been limited, whilst it does also recognize that there is an impact on the parent and they do present emotional and psychological symptoms, in relation to crisis points of their child's illness. Dempsey (2008) offers a thoughtful and practical guide from a parent's perspective whilst caring for a chronically ill child. She speaks from her own experience of the disclosure of diagnosis, coping with hospital and treatment and support. Empathically she goes on to say 'for the parent of a newly diagnosed child, denial is almost natural' (p. 23). She further refers to how they don't want to believe what they are being told and they may even seek second opinions hoping to prove that the diagnosis was wrong. Adding that 'It is as if the conscious mind cannot yet accept the new reality and enters into a period of denial to allow for change and adaption' (p. 23). Davis (1998) offers literature from a

professional viewpoint, whilst giving attention to establishing a partnership with parents, he states how the psychological effect of ‘shock’ is predominately at the diagnosis of a serious illness, adding ‘this is a serious crisis, a point at which significant change has to occur in the parent’s model and behaviour’ (p. 17).

Burke et al (1992) refers to how ‘chronic sorrow is a phenomenon that is likely to occur in individuals with chronic or life-limiting conditions and their caregivers’ (p. 242). Adding how ‘chronic sorrow is a form of grief in that it constitutes a normal relation to the significant loss of normality in the affected individual or the caregiver’ adding, ‘the presence of a disability or chronic condition, serves as a constant reminder of loss and holds the affected individual or the caregiver in an emotional bondage that does not permit reestablishment’ (p. 232). Whilst Dempsey (2008) refers to how ‘a parent can experience grief for the life they had planned or imagined for their child’ (p. 23).

Davis (1987) offers a thoughtful and direct consideration of the ‘grief’ reaction that is present in parents, in response to the birth of their child with a chronic illness. Burke et al (1992) refers to how parents can’t reach a final resolution, for the child not only does not die but they also require more care than other children do. Unfortunately, there is not the same ritual available for families to grieve these losses due to chronic illness, as there are rituals associated with death (Leahey & Wright, 1984).

Dempsey (2008) continues to capture, how important it is in recognizing the parent’s wellbeing along with the consequence, if they can’t cope with their child’s illness. Stating, ‘when a child is diagnosed with a serious illness or condition, the ability of the parent to cope is of paramount importance to the welfare of the child’ (p. 17). Whilst Davis (1998) supports this view, and refers to the well-being of the parents in

all aspects of their lives and if this is ignored or neglected ‘it may be to the detriment of the child and the treatment of the child’s illness’ (p. 32). Whilst Hopia et al (2005) refer to a particular study and they consider another dimension, stating how some mothers have felt guilty about their child’s illness and any sense of pleasure they might experience whilst their child was unwell.

The impact on the family, having a child with a chronic illness.

In the situation where the child’s illness is diagnosed, the family momentarily loses its autonomy because their whole life is controlled by the hospital. The child is obviously dependent on the treatment he or she receives through the hospital, but some parents feel that their child is actually hospital property for a while (Hopia et al, 2005). Rushton (1990) adds that the involvement with the health care system can often be a frightening experience for the family of the chronically ill child. While Glazer-Waldman et al (1992) refer to how the child’s outcome may be uncertain, procedures and treatments are generally painful and invasive, and the environment is very stressful

Leahey & Wright (1984) refer to how the impact affects the family and how the whole family is ill. Reference is made to how this is frequently shown by intense reactions to the initial diagnosis of the illness. Adding that when the family is shocked along with the disbelief of diagnosis, physical symptoms may also occur in family members along with their ability to cope with this initial shock, and almost always, denial is often evident. Paton (1999) argues that denial as a coping mechanism may help families pull through a crisis, whilst also adding that it will be dysfunctional if it is maintained in the chronic phase.

The complexity of symptoms and the impact on all family members cannot be under estimated (Ellenwood & Jenkins, 2007). Reference is also made to when a family member is diagnosed with a chronic illness, the quality of life for the family, regardless of culture or religion, is substantially altered. The family's functioning, resiliency, and ability to manage daily life activities are drastically impacted, as all members experience the emotional impact and physical burden of the child's care. While Rolland (1994) recognizes the importance and pain of all family members he wants to prevent them from being marginalized by aiming to 'mobilize their potential as a powerful psychosocial unit' (p. 2).

Professional support available to parents who have a child with a chronic illness.

Professionals in health care literature focus on the ill child and measures that are sought to ensure the comfort of the person with the illness and what supportive structures are to be put in place. Recognition developed at a later date, as literature now refers to how the illness can be burdensome for parents unless support is provided for them as well, literature has added how parents will experience stress, anxiety and depression, unless they are also helped in the process (Hornby & Seligman, 1991).

Rolland (1987) offers a modest proposal for an optimum belief system based on a flexible family approach that is process, rather than cure-focused. He refers to how, in understanding the family-illness paradigm, this can help and enhance the prediction of the patient's compliance with medical treatment, and the family's adaptation to an illness. Terry (1987) in her qualitative study of parents of hospitalized children found that a parents' greatest need was for information and for

the opportunity for ventilation and support. Whereas, Skipper and Leonard (1968) refer to a similar study and found that giving mothers of hospitalized children additional information and support resulted in a decrease in the level of stress of both the parent and the child (Glazer-Waldman et al, 1992).

Summary.

There is strong evidence that talking therapies can be effective in periods of stress and transition. Therapy can provide an understanding and a focal point for parents to look after their well-being while dealing with difficult times, managing future difficulties, promote social connectedness and help with social isolation. Jackson (2013) refers to how counselling helps people build resilience, psychological control, autonomy and the ability to relate to others, and in turn helps to enhance well being. In a philosophical sense, the biopsychosocial model that Rolland (1994) focuses on, refers to how the workings of the mind affects the body, indicating that therapeutic models should be more recognised as an important aspect to family health. He also adds that there is limited research on counselling parents of a child with a chronic illness, and health care literature is only concerned with the physical care of the child; it tends to neglect the psychosocial needs of the parents, along with the family (Rolland, 1994).

Chapter Three

Methodology

Research philosophy and design

This study aimed to explore the experiences of being a parent of a child with a chronic illness. To explore this phenomenon, a qualitative method was more appropriate in order to gain a deeper understanding of the richness of each of my participants' experience. Silverman (2005) suggests that in order to decide whether to use quantitative or qualitative research methods we should consider our objectives and ensure that these fit with our choice. He states that qualitative studies commonly use small numbers of participants and focus on individual experience, rather than larger numbers with the intent of generalising findings. Additionally the 'bedrock' to a quantitative researcher and the philosophical foundations are rooted in positivism. The positivist perspective holds that there is an objective, observable truth that can be proven and can be used to predict future events (Maykut & Morehouse, 1994). Whereas, my aim was not to measure the effectiveness of my participant as a parent but to explore their unique experience of being a parent with a child with this condition.

Phenomenology is the philosophical approach underpinning my research. By using this approach, I observed my participants experience as it occurred. Maykut & Morehouse (1994) capture the uniqueness of this approach stating, 'reality is variously constructed by each of us, and we bring our multiple meanings to each act and interaction'. Also adding and confirming why this approach is more effective for my research study 'as a result, most human phenomena are the result of multiple causes, which often escape inquiry by traditional scientific methods' (p. 53). My

challenge was eliciting the meaning of my participants' experience and immerse myself in the data I had collected, this was done through the process of Epoché, whilst being conscious of and as far as possible to use a technique of 'bracketing off' my assumptions and beliefs in order to examine how the phenomenon presents itself in the world of my participant. Interpretative Phenomenological Analysis (IPA) acknowledges that it is not possible to suspend all presuppositions and biases in ones contemplation of a phenomenon. And McLeod (2001) also acknowledges the challenge, stating 'the experience and identity of the researcher always influence the findings that are produced' (p. 195).

Qualitative research is derived from philosophy and anthropology and widely used in social science, it has been described by Holloway (1997) as 'a form of social enquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live' (p.1). Additionally qualitative research also represents a form of 'narrative knowing' that is grounded in our everyday experience, and my objective was to capture this essence and use this interpretation.

Sample

The aim of this study was to engage with the personal experiences of parents who have a child with an illness. My initial inclusion criterion was: '*Counsellors who are parents of a child with a life-limiting, chronic illness'.* An advert was placed in the Therapy Today magazine and website, citing my inclusion criteria (Appendix 2) and posters were sent to regional counselling agencies (Appendix 3) along with a letter to ask if they could display my poster on their notice board (Appendix 5). I became aware with retrospect that stating a child's illness as 'life-limiting' was too vague and limiting. So I amended my poster and criteria to state:*' Are you a counsellor with a*

child who has a chronic illness' and sent these posters out to the same agencies (Appendix 4) with a letter to explain my predicament (Appendix 6). This was so I could capture a sample that was a purposive homogenous group for whom the research question was specific and meaningful and which would yield a clearer understanding of the phenomena, as opposed to a random sample. I sent an information sheet to the participants who had made contact with me, this was to confirm and outline the aim of the study in more detail (Appendix 11). I received seven replies from people volunteering to participate and I interviewed 4, as the other 3 participants had decided to opt out of the process for various personal reasons. The group of participants I interviewed were mothers, all from a white British background, and they all had a child with a different diagnosis and varied with age (Appendix 14). Smith, Flowers & Larkin (2012) suggest that 4 participants is sufficient for my research, stating 'IPA utilizes small, purposively-selected and carefully-situated samples, and may often make very effective use of single case analyses' (p. 29). While Patton (1997) confirms that qualitative research uses samples that are small in number, but 'information rich'.

Reliability, validity and trustworthiness

Validity in qualitative research can also be referred to as 'trustworthiness' pertaining to our feelings about the researcher's interpretation and the study's findings (Maykut & Morehouse, 1994). While the aim of quantitative research is generalisability, Banister et al (1994) argue that the aim of qualitative enquiry is specificity. They elaborate that when the unique meanings of the research setting are comprehensively explored with the participant's involvement, validity is increased. To enhance the validity of the study I sent a copy of the transcribed interview to my participants and I have provided an audit trail of my findings in the form of tables and photographs in the appendix to offer how the themes were progressively integrated

until a master theme was established. The inclusion of a literature review also builds in triangulation, which McLeod (2001) proposes is part of the criteria for validity in qualitative research. I am aware of the implications of 'reflexivity' that Elliott & Williams (2001) discuss. And I have kept notes to increase self-awareness of my preconceptions and biases, whilst also being explicit about my own experience with the subject area.

Data Collection

A semi-structured interview took place with 4 participants. I used a scheduled interview questionnaire only as a framework and a focus to facilitate a rich discussion (Appendix 13). The interviews lasted approximately one hour; this offered the chance to change the direction of inquiry to accommodate new insights, and any other comments that were made by my participants or prompts that turned out to work well in the interview process (Knight, 2002). My participants were contacted by telephone and email, and a letter (Appendix 7) was sent prior to the interview with 2 consent forms and an initial questionnaire to verify and record that they matched my criteria (Appendix 8). Once they were happy to proceed, arrangements were made to meet at a mutually convenient, safe and confidential location. I met two at the University of Chester, one at her workplace, and one at her home. On all these occasions I made sure a family member & my partner knew of the addresses and the times. I also phoned before and after my scheduled meeting with the participants. All settings were private and confidentiality was maintained throughout the interview. Before beginning the interview I answered any outstanding questions the participants had, and the consent form to record the interview was signed (Appendix 10), along with the informed consent (Appendix 9). I switched my audio recording on and ensured the participants remained in agreement to proceed and although initially reticent to speak for fear that I may influence the participant, I gradually became more confident

to ask for clarification or elaboration of the questions I had prepared. The interview schedule centred on 13 open-ended questions, with the first 7 being about the participant and their subjective experience around their child's diagnosis and illness, followed on with a further 6 questions relating to any emotional support. The phrasing of the open-ended questions was prepared with the attempt to ask the participants about their experiences but without limiting those experiences to just one, of a range of possible feelings, thoughts or events. Once all the interviews were completed, I transcribed them for analysis purposes. This narrative material was the beginning of the process and the start of identifying any emergent themes (Maykut & Morehouse, 1994). I made notes after the interview as a means of reflecting upon my impressions and interaction with the participant, and I was aware that all these additional data sources could be useful resources for the subsequent contextualisation and development of the analysis (Smith et al., 2012).

By following the BACP's Ethical Guidelines for Researching Counselling and Psychotherapy (2004) this also gave me directions on good practice in data collection and analysis, including the areas of openness and integrity; confidentiality; accuracy; and the disclosure of limitations.

Data Analysis

The interview transcripts were analysed in accordance with the principles of Interpretive Phenomenological Analysis (IPA). This method was used to capture my participant's experiences in an honest and transparent way. I followed the steps according to Smith et al (2012) as shown in Appendix 17. This consisted of analysing the interview transcripts individually. Each transcript was read and reread before a theme was identified. I tentatively organized these themes under each participants name and then explored them in more detail before identifying sub-ordinate themes. I

then printed each participants identified quote on coloured paper, with each participant having a colour each for ease of identification. I cut and separated each one and displayed them so I could identify what themes were emerging or what theme emerged stronger or more significant than any other and arranged these quotes under the emerging theme title. This process identified 14 superordinate themes and 5 master themes (Appendix 15). The subsumption is the analytic process and operates where an emergent theme itself acquires a super-ordinate status as it helps bring together a series of related themes (Smith et al., 2012). IPA is the most appropriate method of capturing my data as it employs this thematic style of analysis, whilst not seeking to be entirely prescriptive about the procedures to be followed. These steps can be seen in a photographic form in appendix 18. As the researcher, I kept a reflexive journal to keep track of my thoughts and feelings whilst transcribing and being immersed in the participants data, this helped separate my own interpretation of; values, experiences, preconceptions and assumptions are that are brought to the process, as the researcher can never entirely step outside their own position in producing their analysis. To capture the true essence of the participant's reflections and to present them with as little interpretation as possible, I also asked my participants to answer a few demographic questions in the interview. These questions asked about the sex and age of the child, what is the child's medical diagnosis, who lives in the household, how long has it been since diagnosis, and what is their religious belief (Appendix 12).

This approach is both interpretative and phenomenological in that it is concerned with the individual's subjective experience and it views the analytical outcome as being based on the joint reflections and frameworks of both participant and researcher whilst also pursuing an idiographic commitment. There is a clear relationship

between the features of Grounded Theory and IPA, and Smith et al (2012) directs readers to grounded theory literature for guidance because it 'adopts a broadly similar perspective' (p. 18). They both aim to identify themes and categories that are progressively integrated until master themes are established and that capture the essence or nature of the phenomenon under investigation. The reason IPA was chosen as the approach in this study was due to the fact that IPA was designed to gain insight into an individual's psychological world, while Grounded Theory was developed to allow researchers to study basic social processes. Smith et al (2009). Claim that because of the depth of analysis that IPA is concerned with, the microanalysis of the individuals experience along with the texture and nuance arising from the detailed exploration, the presentation of actual slices of human life it is not opposed to more macro level claims, but it steadfastly asserts the value of complementary microanalyses, these analyses that may also go onto enrich the development of more macro accounts.

Smith et al (2012) further add, that an IPA study is likely to offer a more detailed and nuanced analysis of the lived experience of a small number of participants with an emphasis on the convergence and divergence between the participants. By contrast, a grounded theory study of the same broad topic is likely to push towards a more conceptual explanatory level based on a larger sample and where the individual accounts can be drawn on to illustrate the resultant theoretical claim (p. 202).

I integrated the concept of 'hermeneutics' that is the second major theoretical underpinning of IPA. The double hermeneutic factor of IPA links with Willig's (2001) argument that it is important to consider the differentiation between the phenomenological contemplation of an event as it presents itself to the researcher, and the phenomenological analysis of an account of an experience presented by a research participant. The research participant's account becomes the phenomenon

with which the researcher engages. Smith et al (2012) argues that successful IPA research needs to combine a position of the hermeneutics of empathy with a hermeneutics of questioning, stating 'thus the IPA researcher is in part, wanting to adopt an insiders perspective' (Conrad, 1987).

In this study interpretations are illustrated by extracts from the transcripts in order that the reader can assess the interpretation of the analysis. The strongest criticisms have been with the way IPA claims to be dealing with 'cognition' and the way people think about themselves and their experience. This confirms the dualistic separation of the mind and body that phenomenology rejects (King, 2010).

Limitations

I am aware that there are limitations to my research. It is a small-scale study with a tight time frame, which will inevitably have an impact on the scope of its findings. Although the sample may appear small, it conforms to the recommended sample size for IPA work (Smith et al., 2009).

Willig (2008) argues that the qualitative researcher seeks to explore individual experiences through the medium of language, this is a social construction and the role of language in IPA is central to the approach, yet this requires the assumption that language provides the necessary tools to capture an experience. It could be argued that the stories and subsequent analysis informs the researcher about the ways in which the participant can talk about a particular experience within a particular context, rather than about the experience itself. Willig (2001) continues to argue that the language constructs, rather than describes reality, the same event can be described in many different ways and may be described another way within a different context. Another limitation to this study, is that it is focused on four mothers experiences, and the themes that have emerged may not be the same as a father's

experience of having a child with a chronic illness, or if it was the child who was interviewed, this is particularly relevant when asking that person to describe their emotional experiences in a manner that captures the subtleties of that experience, as was the focus of this research. These limitations could also be argued that language precedes and therefore shapes experience, as the availability of words to describe a particular phenomenon also provides the categories of experience.

Ethical issues

Ethical approval to carry out this study was obtained from the University of Chester Ethics Committee, and I was assigned a research supervisor. The BACP Ethical Guidelines for Researching Counselling and Psychotherapy (2004) sets out the minimum standards for good practice in research. With reference to this document I sought to minimise ethical issues by choosing to interview counsellors rather than clients or other members of the public, whilst also being relevant and appropriate to my subject area. Elliott & Williams (2001) argue that there are three primary ethical principles in research: avoidance of harm, informed consent, and confidentiality. The counsellors I interviewed all had access to supervision, as I was aware that some of the material raised may have brought up issues. I was aware of consent and confidentiality procedures and I ensured that all my participants were made aware of the purpose and aim of the study, as well as how their narrative material would be used and stored. My participant's anonymity was maintained by allocating them a pseudonym, whilst removing any other contextual details that may of disclosed their identity, or that of their family to maximise confidentiality. The recordings were kept on a memory stick and kept in a locked drawer whilst I carried out the interviews, and will remain locked away until destroyed. The consent form and the information sheet made explicit the right to withdraw from the study at any time, and after I transcribed the interview, I sent my participants a copy of their transcript. I also made sure that I

kept myself safe on the day I interviewed my participants in a mutually convenient safe location, and I advised significant others of the time and place of meeting.

Chapter Four

Findings

The focus of this study is the phenomenological experience of parents who have a child with a chronic illness. I interviewed 4 mothers who had a child with a chronic illness. My four participants are displayed in table 1 below, with further information in relation to their child.

(Pseudonym)	**Victoria / V**	**Julia / J**	**Amy / A**	**Shelia / S**
Relationship to child	Mother / Son	Mother / Son	Mother / Daughter	Mother / Son
Childs age	24 Years old	27 Years old	16 Years old	5 years old
Family members living at home	Mum, Step-Dad	Mum, Sister	Mum, Dad, Brother	Mum, Dad, Sister
Time since diagnosis?	22 years	27 years	13 years	24 months
Marital status	Divorced	Divorced	Married	Married
Age of child at diagnosis	2 ½ years	Birth	Aprox 5 yrs	Aprox 3 yrs
Impact at birth	No diagnosis at birth but had a fear something was wrong with symptoms he presented.	Diagnosis at birth. Couldn't speak or communicate for several days in hospital	Felt something wasn't right from 1 year old; but was told it was too soon to tell or diagnose	Diagnosed when he was around 3 years old; didn't contemplate anything before this
Time when parent started counselling training	When son was 2 – 2 ½ and before her divorce	Trained after diagnosis and after divorce	Trained after diagnosis but had always wanted to do counselling as a career progression	CBT counsellor before diagnosis

Table 1.

My interpretation of the resultant data highlighted five master themes, within these main themes a further 14 superordinate themes evolved, which link to, affirm and expand upon findings from my literature review.

Master themes identified:

1. Somatic experience
2. Emotional & Psychological impact
3. Behavioural expression
4. Cognitive expression
5. Personal relations

The analysis of the interviews is presented accordingly. The main themed groups and their corresponding superordinate themes are used in table 2, to present the outcome. When part of a transcript is cited, a pseudonym name is used to identify the participant and a line number is used to indicate what part of the transcribed interview it was taken from. Within the transcript, brackets are used around a related person that was quoted in the interview. Each master theme is presented in bold type and each superordinate theme is underlined.

What clearly emerged from these groups was the significant impact that their experience had on them at diagnosis and prognosis, along with how they responded to their child's illness (further reference is made in Appendix 16). 14 themes have been classified into 5 main master themes, to illustrate the research outcomes and shown in Table 2:

Master theme	*Superordinate theme*
1. Somatic experience	1. Shock
2. Emotional & Psychological impact	1. Loss 2. Fear 3. Anxiety & Stress 4. Helplessness 5. Sadness & Hurt
3. Behavioural expression	1. Positive behaviour & Resilience 2. Taking control & Resilience
4. Cognitive expression	1. Denial 2. Disbelief 3. Coping 4. Preoccupation with child's illness
5. Personal relations	1. Loneliness 2. Support

Table 2.

Somatic experience

Superordinate theme 1.1: Shock

All the participants were able to recall with clarity the time they were told of their child's diagnosis, and the memory of that moment served to remind them of their feelings. The strength of emotion evoked by this recall was apparent for 2 participants, as they suspected something was wrong at birth, and yet it went un-diagnosed. The repeating of words, such as 'slap' by Victoria and Julia's use of 'I couldn't speak or communicate' encapsulates the depth of the shock felt. A nurse described Julia to her husband as being 'catatonic' as she was being discharged from the maternity ward; this was explored in depth in our interview, and was related to a sense of having had a traumatic experience.

Victoria; She said to me, you do know he has got (Diagnosis) don't you? and it was as if someone had thrown a bucket of water over me, I had put all of that behind me for a time, I felt as if she had slapped me. Line 176-178

Victoria; So even though I'd had that 18 months before when I had said has he got this, and I had seen it and they had said no and I had put it back as if I had never heard the phrase before and it really was like a slap in the face. Line181-183

Julia; Just keep your eye on her she has been like 'catatonic' while she has been with us. Line 43-44

Julia; The shock was coming around from the operating theatre knowing there was something wrong and that's why coming around from the aesthetic I couldn't speak or communicate. Line 209-211

The strength of emotion evoked by this recall was apparent in the interview for both Shelia and Amy, but in different ways. This had depended on if they had suspected something was wrong during the time leading up to the actual diagnosis. They both

did not suspect that anything was wrong with their child at birth and they both received the diagnosis at a later date. The shock is more apparent in Shelia's narrative and Amy refers to it being more a process as she had suspected something leading up to the diagnosis.

Shelia; I had the shock of my life, as although I knew something was different with his heart or kidneys, I never really thought there was anything wrong with him. Line 457-459

Shelia; for me, I went through the process which is in books, like shock, denial, but I wasn't aware of it shall we say, I just kind of coped in a way, so I was oblivious to it but I'm not now. Line 6-8

Amy; I think the actual confirmed diagnosis probably was something we had already, we were gradually becoming aware of and it was more of a process rather than an event. Line 5-7

Amy; It's a lot. It's a whole major life adjustment. Line 288

Emotional & Psychological impact

Superordinate theme 2.1: Loss & Grief

Victoria and Julia talked about the physical sense of loss. Victoria emphasises a sense of loss when she had not realised what she was wearing, as her maternal instincts kicked in and the internal need to feed her baby was consuming. While Julia heard other babies cry on the maternity ward, which added to a further sense of loss.

Victoria; I got a phone call from the hospital and they said 'oh (child's name) awake and he needs a feed' I had just got out of the shower and I literally put a dressing

gown on, wrapped a towel around my head, jumped into the car and drove to the hospital to feed him. Line 78-81

Julia; Where is my baby, you can imagine? And I would hear other babies and it was very difficult. Line 67-68

Julia; I wanted to touch him and to spend time with him and to bond with him. Line 76-77

Victoria, Shelia and Amy talked about the sense of loss in relation to what they expected and envisaged for the future.

Victoria; It's kind of a loss of expectation as well for me. Line 390

Shelia; Loss in the sense, what I thought our family life was going to be because family life now has been impacted by this illness and things that do and don't happen because of that. Line 11-12

Amy; Was it wrong for me to mourn for the child I never got. Line 334

Amy; It's a loss of a sort of milestone they reach and its not going to be the same. Line 33-34

<u>Superordinate theme 2.2: Fear</u>

Julia repeated how fearful she felt, while Victoria and Shelia used the energy they felt from their fear by taking control and doing something they felt would help or benefit themselves.

Julia; I was frightened all the time, all the time; I was frightened all the time. Line 110

Julia; I was anxious and I was frightened all the time, I couldn't settle I couldn't rest and I had nightmares. Line 246-247

Julia; It was like I was anticipating the very worst and what was I going to do, I was trying to plan for it, it was just ridiculous but I was fearful. Line 336-337

Victoria; They were saying we think he is ready to start integrating into main stream school and then I didn't want him to then because it felt so safe were he was, so it was completely the opposite then, of me fighting no he doesn't need a special school he is going to be ok there is nothing wrong with him he can cope, to suddenly being really frightened about the idea of him going to a main stream school and complete reverse really. Line 370-375

Shelia; When he was diagnosed I went off and I researched everything the horror stories and everything and my husband did none of it, he still doesn't do any of it, I do all of that and its not that I think that my sons going to end up in the worst case scenario but then I'm prepared, thinking ok that could happen and we are going there and potentially it could be. Line 145-149

Amy's husband observed and reflected back to her, what he felt was her sense of fear.

Amy; You are looking around at the environment to see what hazards there are and what triggers there might be for difficulties. My husband described it as constant vigilance. Line 137-138

Shelia confirms how she has still not fully integrated how fearful she feels.

Shelia; Fear of his future and I guess my acceptance, I haven't accepted it. Line 14

Superordinate theme 2.3: Anxiety & Stress

Victoria emphasizes the impact as feeling 'traumatic' and later on in the interview she refers to this fear as a form of 'anxiety, although it is very evident that these feelings are still very present and stressful, even reflecting on them now.

Victoria; That was very traumatic because it was almost like 'hang on what's happening' there was a sense of, I had gone in expecting to have this baby and all of a sudden he has gone and I don't know whether he is ok? Is he going to die? Nobody was answering any questions or telling me anything. Line 26-29

Victoria; Yeh some sense of things not being quite right like a fear of what's going to happen all most, maybe more of an anxiety. Line 320-321

With the impact of the stress, Victoria showed the physical symptoms of her experience.

Victoria; More stressful, going backwards and forwards and trying to express milk and its not very surprising really that after about I think it was 3 weeks that my milk just disappeared, probably with stress, I was upset about that and I felt guilty about that because I had fed my daughter for about 9 months. Line 101-105

Amy referred to feeling anxious, in relation to her unpredictable future.

Amy; After it had been confirmed I felt more anxious about what her future might hold. Line 25-26

Superordinate theme 2.4: Helplessness

Julia and Shelia felt the sense of helplessness whilst their child was being cared for and treated in hospital. This power imbalance is also felt in other areas of their life. Julia refers to 'everything', whilst Shelia refers to how she felt alone, especially at a time when she needed a professional opinion and support.

Julia; At the time you do feel powerless and your in everybody else's hands they've definitely got control over everything. Line 122-124

Shelia; His consultant was off when he relapsed this time and that was probably the

most alone I have felt with it since the initial sort of diagnosis. Line 304-305

The impact of feeling she was doing something wrong, gave Victoria a heightened sense of helplessness. Whereas Julia felt helpless, and passively followed instructions that were given to her.

Julia; I was upset at the thought of having my breast milk and no baby and they gave me tablets to take the breast milk away. Line 125-126

Julia; I did I suppose agree with it because I was so upset. Line 130

Victoria; I think even if someone had said to me its ok to be upset, its ok to be like that, but I had this sense I was doing something wrong. Line 646-647

Superordinate theme 2.5: Sadness & Hurt

The sadness was evident in the way Shelia and Victoria spoke about these experiences in our interview. It is also evident in the way Shelia phrased her 'broken heart' and 'silent tears' and how Victoria has phrased 'if he only lived for a couple of days'.

Shelia; You might look really pale and ill and it breaks my heart to look at you but you know we had that little snuggle and its nice, we laughed over something and do you know what its not all been bad, its picking out the little things that we don't generally notice a lot. Line 92-95

Shelia; I had these silent tears dripping down my face and the doctor went out of the room and my husband said what are you crying for. Line 462-463

Victoria; Even if he was there and only lived for a couple of days, he was still there and it was like that acknowledgment wasn't there and I can remember that very clearly, that feeling of sort of hurt and that trauma, and I can remember one of the nurses saying oh come on now snap out of this because I was so tearful for a couple

of days, I just couldn't stop crying. Line 66-70

Victoria, Julia and Amy also felt saddened and hurt in response to how others had behaved towards them. Amy refers to being upset in response to her daughter's ability, and Julia felt hurt with how the other mothers responded to her being on the maternity wing with no baby at her side, as he was having surgery in another hospital, while Victoria referred to how she felt her husband lived and spoke with a continual disappointment, when he referred to their son.

Amy; If she couldn't express what she wanted she would get very upset and I would feel really upset on her behalf. Line 86-87

Victoria; There was disappointment all the time with my ex husband, it was almost 'palpable' you know you could almost see it and he would always say he wasn't disappointed but it was there it was very evident. Line 441-443

Julia; I think the other mothers must have known and I don't think they wanted to kind of communicate with me, either because they didn't know what to do or what to say. Line 70-71

Behavioural Expression

Superordinate theme 3.1: Demonstrating a positive attitude & Resilience

My participants presented during the interview, a positive element of living with their child's chronic illness, which I believe is at the heart of the daily psychological battle. Amy, Julia, Shelia and Victoria, all talk in the present tense about reward, hope and the future.

Amy; I suppose, I have coped because I suppose there is some sort of reward in connecting with someone who is hard to connect with, there is some sort of satisfaction in that. Line 176-178

Julia; I was very positive about the future and I was going to do everything I needed to do, I had plans. Line 385-386

Shelia; I don't look at that as a morbid sense, I look at that as do you know what 'today is today and it's a good day' even when its really difficult there is always a good part in that day and its looking for it. Line 87-89

Shelia; I do think all the fundraising we have done has really helped me cope because again, I guess it goes back to how I have some control and trying to do something to give a more positive future. Line 228-230

Victoria; I just thought that was really the beginning of the end for me when I realised just how he was feeling inside and it was totally different to me because I had lots of hope for (Son's name). Line 470-472

Julia also reflects, but in a past tense, why she found it easier to cope with her sons chronic illness.

Julia; I think having a disabled sister was a main influence on what I was going to do on life, I have been brought up with disability so it didn't have that impact on me, it was normal. Line 353-355

<u>Superordinate theme 3.2: Taking control & Resilience</u>

Amy, Victoria and Shelia showed resilience by not being overwhelmed by their child's illness in the form of 'taking control' and demonstrating a 'can do' attitude, in relation to life and their child's illness.

Amy; I suppose I have learnt to have time for myself more, which I didn't so much then, so I have learnt that I need time for myself to do some of my own things. Line 183-184

Amy; I have had to stand up and say 'well actually this is a lot worse, your minimizing it or this is really important to me and your not recognizing that'. Line 245-247

Victoria; So any exercise that the physio gave, would be done religiously and everything was done that I could, over and above the things they were asking me to do, to try and bring him on, develop him mentally and physically. Line 235-237

Victoria; I was determined that he was ok, he can go to an ordinary nursery but there is no need to go to a special one and I really did fight for that. Line 250-252

Shelia; Although I know I can't control his illness, I can do certain things to try and keep him well. Line 143-144

Julia and Shelia further demonstrate resilience by acknowledging what helps them cope, or not in Julia's case.

Julia; I remember my GP coming to see me and giving me a prescription for anti-depressants, which I was not going to take, I think we got them and I flushed them down the toilet I was never going to take them. Line 237-239

Shelia; I would rather know potentially what's there, than imagine things. Line 152

Cognitive Expression

Superordinate theme 4.1: Denial

Victoria and Amy now acknowledge how they processed denial when they were told of their child's diagnosis. Recognizing the denial is part of the process of acceptance, which has been referred to in the discussion and literature review.

Victoria; She said no, categorically no and I suppose and its very easy to do, I thought great there is nothing wrong with him, so I put the blinkers on. Line 153-155

Victoria; And then I suppose you could say I was really stupid for not following my instincts but it was easier to hear 'no there is nothing wrong'. Line 204-205

Amy; It was like a gradual process of realization and denial was certainly there to start with during that process. Line 23-24

And yet, all of the participants showed a sense of filtering by using conditioning words of: couldn't, didn't, don't, isn't, as this allows them to only see what they wanted to see. Julia repeated OK, three times so she could try and integrate and believe what was going on.

Julia; I couldn't think anything for me because I think I was saying in my head I'm ok, I'm ok. I can't speak to you and I can't tell you but I am ok and apparently I didn't speak for quite awhile. Line 32-34

Julia; I didn't think at the time, that they thought he was going to die. Line 257

Julia; I do remember my health visitor telling me early on that marriages with disabled children do break down and I thought why are you telling me that, I don't want to know that or hear that, that's not going to happen to me. Line 377 -379

Victoria; It was something about me needing to distance myself, this isn't happening, get on with normal life, this isn't going on and this isn't happening. Line 84-86

Shelia; I need to write about his journey and I'm like 'he's fine; he doesn't need it as he is not ill. Line 29-30

Amy; We were wondering what it was and people started making sort of observations and suggestions. Line 9-10

Superordinate theme 4.2: Disbelief & Confusion

Shelia understands how disbelief is part of the process to acceptance, as she is a

practicing CBT therapist and she reflects on her cognitive thoughts throughout life and our interview.

Shelia; At times I accept it, very rarely, a lot of the time I'm in disbelief and because his illness is as we describe a 'roller coaster' and we are always on this roller coaster, we hope we get more highs than downs but unfortunately we get an awful lot of downs but when we are on a high, I guess I sort of feel like 'its ok' its gone away now. Line 16-19

Victoria repeats her words, in disbelief as she reflects on her experience.

Victoria; She said 'no, I don't know what is making you think that'? And I said but there are things they're about the way those children are, the reflexes, the sort of a bit floppy. No she said there is nothing there and no evidence of that at all. Now they must have known, they must have known. Line 147-151

Victoria; I thought what does it mean, what does it mean and I looked in medical books to try and all of a sudden to try and find out what that meant. Line 183

Julia describes her sense of disbelief by using alternative words and thoughts.

Julia; It feels very surreal. Line 102

Julia; This was only 6 weeks and I hardly had any time with him. Line 188

<u>Superordinate theme 4.3: Psychological coping skills</u>

Shelia and Victoria showed different and varying ways of how they coped. Shelia assumed that is how you should behave in a crisis, whilst Victoria uses her energy to filter the reality of his diagnosis, by not having fatalistic thoughts.

Shelia; I didn't quite realise when he hit that third relapse the significance until after because we cope don't we, we cope in a crisis. Line 132-134

Victoria; I don't know whether you would call it a coping strategy but from that time of that diagnosis, I would say it became my mission to sort of prove them wrong, in a way so I suppose that is denial isn't it? Not that he hasn't got it, but he is going to be ok. Line 230-233

Whereas, I found Julia talked freely about how she felt she has coped with her experiences, and saw this being an integral part of the process.

Julia; I think you just go on automatic because you can't think about what is actually really happening because if you did you couldn't cope. Line 140-141

Superordinate theme 4.4: Preoccupation with child's illness

Victoria takes a holistic view and integrates her energies into to how she wants to view her reality, whilst also contradicting how she wants 'normality'.

Victoria; They never treated him any differently to how they treated my daughter or their children or any special treatment. Line 280-281

Victoria; Seeing some of the children that had (Diagnosis) that was at the other end of the spectrum and sort of really appreciating that (Son's name) wasn't as badly affected as some of them, I think I was becoming more aware of other people and how other people perceived those kind of things. Line 352-355

Victoria; I wanted my energy to be with (Son's name) and helping him with as much as I could in practical ways. Line 527-528

Shelia and Amy focus on how they deal with their child's illness, internally. While Julia takes this same view, but her son was in hospital at the time she recalled, which triggered these fatalistic thoughts.

Shelia; I will stay up quite late, but I also know that I stay up that late because it's the only time I get for me really. 395-396

Shelia; Everyone is safe and they are in bed, they are asleep and everything is ok with the world in some respects. Line 398-399

Shelia; If we think of us as a couple then that has changed quite significantly because the focus is on our son. Line 405-406

Amy; She was very dependent on me to anticipate what she needed. Line 27-28

Amy; Even now I am trying to make her world better for her. Line 64-65

Amy; I do a lot of work speaking out for her because she cant voice it really. Line 67-68

Julia; It was quite scary, it was quite frightening actually and I will be honest with you there was a time I thought this child is going to die and its going to be my fault, its going to be something I have done while I am holding him. Line 86-88

Amy made judgments whilst being pre-occupied with their child's illness. Amy's sense of identity is ravaged with being what is and isn't visible, including herself.

Amy; Because its so much part of her, it's not like somebody who's got, possibly a physical condition you can forget about. Line 128-129

Amy; Something that is internally wrong you may be able to transiently forget about for a few hours, whereas with my daughter you have to always, it's always there. Line 131-133

Amy; I suppose I became visible when I was fighting and speaking out for my daughter. Line 200

Personal relations

Superordinate theme 5.1: Loneliness & Feeling disconnected

Julia and Victoria highlight how lonely this experience has been for them, they have

also lived with their child's illness the longest as they are both in their teenage years now, and they are both the oldest of the children with a chronic illness.

Julia; Nobody did anything to help me, infact my feeling around that time is, they left me alone. Line 46-47

Julia; They were all panicking so I knew in my heart there was something wrong and they then put me into a room on my own. Line 26-27

Victoria; They whisked him straight away, I didn't even get the chance to see him, they whisked him into the baby unit straight away and I was kind of left. Line 21-22

Victoria; There was this sense that people aren't coming to see me or sending cards if they don't know what is going to happen to him. I was very clear about that, that's how it felt to me, because they don't know if he was going to die, they don't want to send me a congratulations card, but he's here and I was very, very aware of that. Line 58-62

Shelia talked about how it felt as a married couple. Their child's diagnosis is more recent than the other participants.

Shelia; We did initially and still sometimes do, feel very lonely really and people don't understand it. Line 294-295

Superordinate theme 5.2: Emotional support

Shelia and Victoria talked about how important it was to have their friends to talk to for support; this was expressed in a past and a present sense.

Shelia; I think the biggest support has been from other parents with a child with this illness. Line 414.

Victoria; I think the biggest support was from my friends. Line 564

Amy spoke of how important it was for her to feel supported by her husband and how they had to learn to integrate and be conscious of supporting each other, whilst also contemplating how her family have supported her, but in a different way.

Amy; I think mum understood, my sister has always tried to make it, like its normal. Line 313-314

Amy; Obviously it was somebody else taking a lot of energy of us and taking a lot of time away and we had to learn how to support each other. Line 355-357

Julia emphasises how important the professional support was for her at a crucial time. Although further references were made to how this support was not evident with other professionals, and if anything, she felt let down by the nursing staff she had contact with.

Julia; I had a good health visitor, I had a very good health visitor who supported me very much and she came into the hospital before James came home. Line 296-297

Amy has made promising and important point with regards to support.

Amy; I have got help and strength from other people because I have been able to voice my difficulties to other people; I haven't just kept it to myself. Line 228-229

Summary

Strong themes emerged from the participant's interviews, which generally fell in line with existing literature. Each emergent superordinate theme stands alone as a discrete concept, but they can also be appreciated within the whole context of master themes. With further reflection of the analysis, it could be argued that the themes influence each other and the emotional and psychological symptoms presented are infact part of the transformations that happen at their child's diagnosis and during

their child's illness, and how this has impacted on how they view their future. This sudden change in possible future self may be the cause of the intense emotional reaction to the diagnosis, and the fear of the unknown self. But what has also been present is positive thinking in relation to resilience as they struggled to make sense of their child's diagnosis and their uncertain future. These outcomes will be discussed in greater depth within the next chapter.

Chapter five

Discussion

The participants in this research study answered questions about their awareness and experience of being a parent of a child with a chronic illness. There was a lot of strong themes that emerged from their narratives, and this will be discussed within this chapter, along with references to the analysed literature researched.

The most prominent theme that emerged was shock as the participants reflected on their experience. This came under the master theme of somatic, as three out of four of the participants reflected on the physical sense of the diagnosis in the sense of a 'body shock' with the disclosure of diagnosis and because the prognosis was unpredictable. All participants gave evidence that points to the diagnosis as being a surprise, including one participant when the diagnosis was eventually confirmed. Davis (1998) captures this impact, referring to how at the disclosure of the diagnosis 'parents often describe a state of shock, numbness or confusion. They talk about not being able to understand what is being said' (p. 17), whilst adding to this confusion, he refers to how there is a 'turmoil of questions, images and ideas in their head' (p. 17). Throughout the interviews however, all participants gave evidence to the process of gradually coming to terms with these painful feelings. The recall of this time was apparent for two of the participants as Victoria reflected on it as 'a slap across the face' whilst Julia said she 'couldn't speak or communicate' once she was told. These statements encapsulate the depth of the shock they felt. Shelia also had 'silent tears' when the consultants disclosed and explained the diagnosis of her sons illness, she also referred to a 'numbness' she felt at this time. Amy felt she gradually

became aware of her child's condition due to it being physically evident over the three-year period before diagnosis, yet the confirmation still felt like a shock to her, she also felt confused why it hadn't been diagnosed at an earlier time. Hornby & Seligman (1991) refer to how there is a new focus on the parents in their literature, whilst recognising a period of adjustment for the parent, they also support the notion that parents initially respond with shock, disbelief, and disorganization, and this eventually gives way to acceptance. While Dempsey (2008) states in her book how denial is part of the adjustment process, adding how denial can also take on the form of optimism, hoping and asserting that the prognosis is wrong and that a cure will materialize. This process was evident with all the participants at different stages of their child's diagnosis and prognosis during the interview. Victoria highlights how 'she put the blinkers on' while Julia highlighted how she 'didn't think at the time, that they thought he was going to die'. It's evident that denial is part of the adjustment process, along with acceptance, and its not just exclusive to the time of diagnosis.

The emotional and psychological impact the participants described in the interview, has been related to; Loss, Fear, Anxiety, Stress, Helplessness, Sadness and Hurt, respectively. All the participants talked about their 'loss' and linked it to various times. Victoria and Julia referred to the physical sense, when they experienced not being able to hold their child at birth. Julia referred to how she could hear the other babies cry nearby whilst knowing she couldn't be with her son as he was in another hospital having treatment. Not only did she not hold him she felt a deep sense of loss at this time, as bonding with him at birth was crucial to her and her beliefs. Loss was recalled in all the participants, in the sense of the milestones and future expectations that they had all anticipated, before and after giving birth. Amy reflected on these past difficult times of reflection and asked me in our interview 'was it wrong for me to

mourn for the child I never got?' whilst Victoria referred to her 'loss of expectation'. Dempsey (2008) confirms these different senses of loss as she refers to her own personal experience, and sense of loss as being a mother herself, she refers to her 'loss of control, loss of the old life, loss of time with the child, and loss of the life that the parent thought they had created for themselves and their family' (p. 23).

It was evident in all the participants, the feelings of anxiety and fear that linked to their response of the uncertainty of their child's future milestones and health. They all talked about what may happen to their child, with a realization of how unpredictable life is, whilst acknowledging that these thoughts and feelings have been built on what has already happened to them, there was a sense of trying to establish what is predictable with a sense of sadness, whilst reflecting and wanting to feel safe in the world. Leahey & Wright (1984) refers to sadness as being commonly seen in families with chronic illness, and it is often a sign of resignation that may recur whenever there is a new crisis or another developmental milestone that has been missed or delayed. Whilst also appreciating that the way in which an individual is affected emotionally and psychologically is dependent on many factors and some of these include the nature of the illness itself, its severity and the treatment involved. Sadness was also referred to in a different sense; I believe the participants attached sadness to the hurt they felt internally and the external demands of life, so I linked these two together in the emergent themes as being related to one another. Shelia reflected on her internal experience as a 'broken heart' and Victoria referred to how she 'couldn't stop crying' and how 'tearful' she felt at times. Amy, Victoria and Julia expressed their sadness and hurt, referring to how others have made them feel like that. Victoria refers to how 'palpable' her husband's disappointment was with regards to their son's diagnosis and the quality of his future life. And Julia's hurt was

felt as other mothers avoided her on the maternity wing. Another factor to contemplate and consider is, the depth of impact felt by the participants, Katz (2002) found that the 'mothers of critically ill infants tended to deemphasize the severity of the child's illness and the impact it had on their lives' (p.12), and while I believe the participants painful experiences and the complexities of each one is unique, I also had an 'insiders view point' through my own experience as a mother of a child with a chronic illness and I believe that I may also deemphasize, but I recognise this as a form of self-protection for myself.

The emotional and psychological impact that I have focused on in my research, has also made links and referred to this experience as traumatic stress. In 1994 the official definition of trauma was broadened to include events that involved actual or threatened death, serious injury, or threat to physical integrity of self or others. Traumatic stress has been identified in relatively new populations, including those who are suffering from protracted illness or who have a loved one, especially a child, experiencing a serious illness (Morrison, Bromfield & Cameron, 2003). Whilst appreciating that trauma also creates a loss of faith that there is any safety, predictability, or meaning in the world, this links to the participants experience in the context of the loss, anxiety and fear that has been discussed.

In addition to trying to manage the actual illness on a daily basis, the profound nature of the emotional and psychological impact on parents can also lead to feelings of helplessness and hopelessness, which was evident in three of the participants replies. Julia's response of 'I did I suppose agree with it because I was so upset' confirms the complex nature of not being able to make decisions or recognise what was going on, because she was so upset at the time, whilst also trying to establish

her new identity as a mother. This is linked to how Hopia et al (2005) captures and refers to, how hard it is to accept the loss of autonomy. While Rushton (1990) refers to how parents are often overwhelmed with an incredible sense of not knowing what to do, how to act, or to whom to turn for advice or information. Adding how such an experience often threatens the family symmetry and places serious strains on the parent's resources and coping abilities (Anderson & Davis, 2011). Variables influencing the perception of a child's illness have made links to the individual's knowledge, capabilities, life experiences, and sociocultural background. Copeland & Clements (1993) found that parents who cope and adapt less successfully to the child's chronic illness tend to have a more negative and fatalistic attitudes toward the child's illness (Katz, 2002). I found no evidence of this with the participants in this study, but it is an interesting element to consider for future studies; examining what are the factors that trigger this 'fatalistic' attitude, what is it that makes the parent less able to cope and adapt to their child's illness, and what type of support is needed for these parents.

A theme that never emerged in the interview with my participants, but literature has emphasized a link has been made to parents of children with a chronic illness, is anger, guilt and frustration. Dempsey (2008) states in her book that anger and frustration are common emotions at the time of diagnosis, stating 'all parents feel a sense of guilt' in their normal everyday activities, along with how 'diagnosis of a chronic illness they often assume they are in some way responsible' (p. 23). While Walker (1983) adds to this theory with an alarming element of how these feeling could be displayed or secretly hidden, stating how the person in the family who may secretly feel most helpless, angry and desperate is the parent. And by having the intense involvement with every aspect of their ill child's life, this may serve as

protection against these feelings. Davis (1998) reflects how these feelings may be towards others, referring to how ‘parents may feel anger towards strangers who stare at their child’ and how they may feel embarrassed because of the ‘seemingly odd behaviour of their child’ adding that they may even feel ‘frustrated at the constant need to explain what the problem is’ to whoever asks questions about what is wrong with their child (p. 30).

To understand this phenomenon further, I included other strong themes that emerged from the interviews. A symptom that may be overlooked or not seen as debilitating is the sense of loneliness that is felt with parents, in relation to their personal relations with others the potential support they receive. Davis (1998) reflects on how some families become isolated as a result of the disease, whilst some families deliberately withdraw because of the disappointment they feel towards others who do not seem to appreciate the difficulties they face. One participant explained in the interview, how she has started a ‘Facebook’ support group for mothers who have a child with the same condition as her son, she referred to how it has ‘really helped her cope’ by not feeling alone in the world and being able to talk to ‘like minded parents who use the same medical jargon’ whilst feeling understood and without having to explain every painful detail of her sons condition. Another participant explained how she had set up a local support group for parents of children with ‘illnesses’, but concluded it wasn’t such a good idea for her as she felt she was offering the support others and she was not receiving the support she had wanted from her idea. It also highlights the need that parents do want support in some form, which can enhance and add to how they already cope with their child’s illness.

The findings from this qualitative study has implications for the practice of a variety of professionals who work in the health care and therapeutic settings with parents of children with a chronic illness. What has already been explored in this study can add to an already established base of awareness of the parent's needs or what other support measures could be offered. All the participants in this study explained how at differing times of diagnosis or prognosis, they were advised 'insensitively' by professionals in the health care setting, adding, how they would of benefitted from a more empathetic understanding of what they were going through along with feeling supported. Establishing links between the hospital, health care settings and counselling services would be one method of improving the availability of support offered to parents, and through collaboration of health and nursing practitioners more mothers could be identified and supported during their child's stay in hospital and follow-up consultations. I recognise that some hospitals do have an external therapeutic base they can make referrals to, but from my own experience this doesn't happen, yet having an internal, readily available therapeutic practitioner that could be called upon, may influence the parents perception of the child's illness by reinforcing and encouraging them to express their feelings and concerns regarding their child's illness and by offering professional therapeutic help. Ellenwood & Jenkins (2007) study also confirms this, referring to how 'child caretaking' is so demanding that often the family is confined to their home, hospitals, inpatient treatment centers, and the doctor's office. The quality of life for these families is often minimal as they lack social interaction, friends, family support, and family cohesiveness. And this is especially important for mothers who tend to take the main responsibility for the care of the child themselves. Katz (2002) study further supports this belief, stating, 'parents experiencing stress as a result of the child's chronic illness have described the need for information, emotional, and practical support (p. 2). Along with Gordon &

Benishek (1996) who believe that counselling should provide opportunities to discuss issues of self-esteem, altered roles, and personal concerns related to the clients unique perception of the illness experience, and how counselling can aid in understanding and facilitating the grieving and adjustment process.

Chapter Six

Conclusion

In concluding this dissertation, I feel it apt to refer to a quote from Rolland (1994) 'Illness, disability, and death are universal experiences that confront families with one of life's greatest challenges' (p. 1). This quote has echoed and stayed with me as I wrote my dissertation. Not only as a reminder of my own personal experience of having a child with a chronic illness, but as a reminder to why this study is important, not just for me, I also wanted to give my participants a voice, whilst also suggesting there is a need for further research in this area.

I initially had numerous concerns and questions. Would people agree to take part? Would counsellors feel threatened by the study? What would parents think of me asking such personal questions? What effect would the interview questions have on the participants? Did I have the right to intrude on their private lives? What would be the quality of the data I collected? Would the data be of any use? Who would be interested in such a study? However, in every step of the research I was met with encouragement and cooperation. Those who did participate were helpful, open and honest in their disclosures about their experiences and I hope I have managed to make some meaning of this phenomena. Whilst I understood some of the areas covered, it was also a privilege to be part of their journey and communicate not as a researcher but as a parent as I was invited to share in their private world, which was painful and distressing, as I feel my own world is at times.

I would also like to conclude that having a therapeutic practitioner within the hospital setting would help this type of support that I have suggested happens to parents of

children with a chronic illness, and it is even more important and needed at crucial times, whilst also alleviating the professionals in the medical setting, that need to concentrate on their specific area of practice.

Recommendations

Although researchers have identified a plethora of risks, stressors, and interventions for families with a chronically ill child, there is a scarceness of evidence-based literature. This population is in urgent need of evidence-based, empirically proven interventions for psychological and emotional support. I believe having counsellors as participants has enhanced this study, as they would have received a certain amount of personal development within their training. Further studies that don't use this purposive homogenous group for whom the research question was specific and meaningful may limit further investigations that can yield a clearer understanding of this phenomena. I also believe that the parents consented to this study because they felt reasonably confident about their child's diagnosis and because they value the space in which they can discuss their personal experiences in depth, whist adding to a research base.

These qualitative studies are essential to counselling practice and service providers. Jackson (2013) supports this in a recent article, referring to how counsellors see the pain of their clients, whilst referring to how the problem is known by the counsellor but it is contained within the privacy of the counselling room, and they are not doing anything with that knowledge. She suggests how practitioners could help build on this evidence base by collecting data on symptoms of mental distress and counsellors could be measuring wellbeing using validated scales such as WEMWEBS (the Warwick-Edinburgh Mental Wellbeing Scale).

Areas for future research

There is potential for future research in this area and to expand on the findings of this study. There are also additional and similar areas to explore; the experiences of fathers in the UK; fathers from another cultural background; the experiences of grandparents or siblings, and other relationships that are formed with a child with a chronic illness. Questions around what are the perceived psychological pressures, life changes and feelings, do they differ from the women participants included in this study?

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List of Appendices

APPENDIX 1.

Research Strategies;

Key Words	**Databases**
Counsellors Counselling Psychotherapists Therapy Impact Working with Living with Experience Carer Parent Family Families Relationships Child Children Life-limiting illness Chronic illness Illness	University of Chester Library Catalogue PsycINFO PsycARTICLES and the Psychology and Behavioural Sciences Collection Chesterrep CINAHL Lexis Library SocINDEX Zetoc Alert PubMed British Library Catalogue BACP website; (Taylor & Francis Online) Google

APPENDIX 2.

Masters student at Chester University seeks participants to take part in a research study. If you are a counsellor who has the experience of living with a child with a life-limiting, chronic illness; with 2 years post qualification experience and 2 years have elapsed since your child's diagnosis. Please contact me for more information if you are interested in participating on ……

Dates & deadlines

Ten issues per calendar year disrupted approximately 19th of each month, excluding January and August.

Advertising rates;

Display mono; In Classified (price per word) - £1.16

Target audience

Counsellors & psychotherapists in independent practice

The charity/voluntary sector

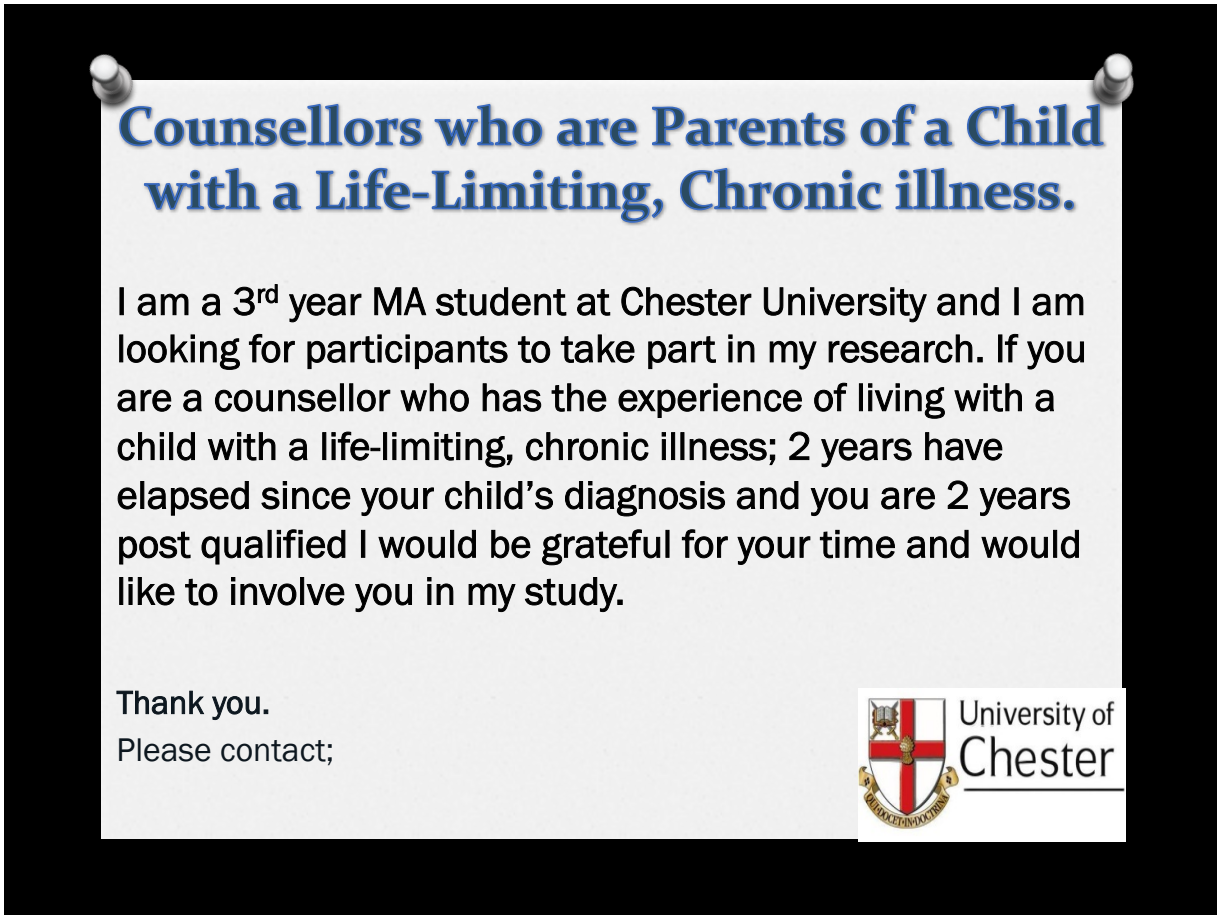
Students

Health, education, youth and the commercial workplace

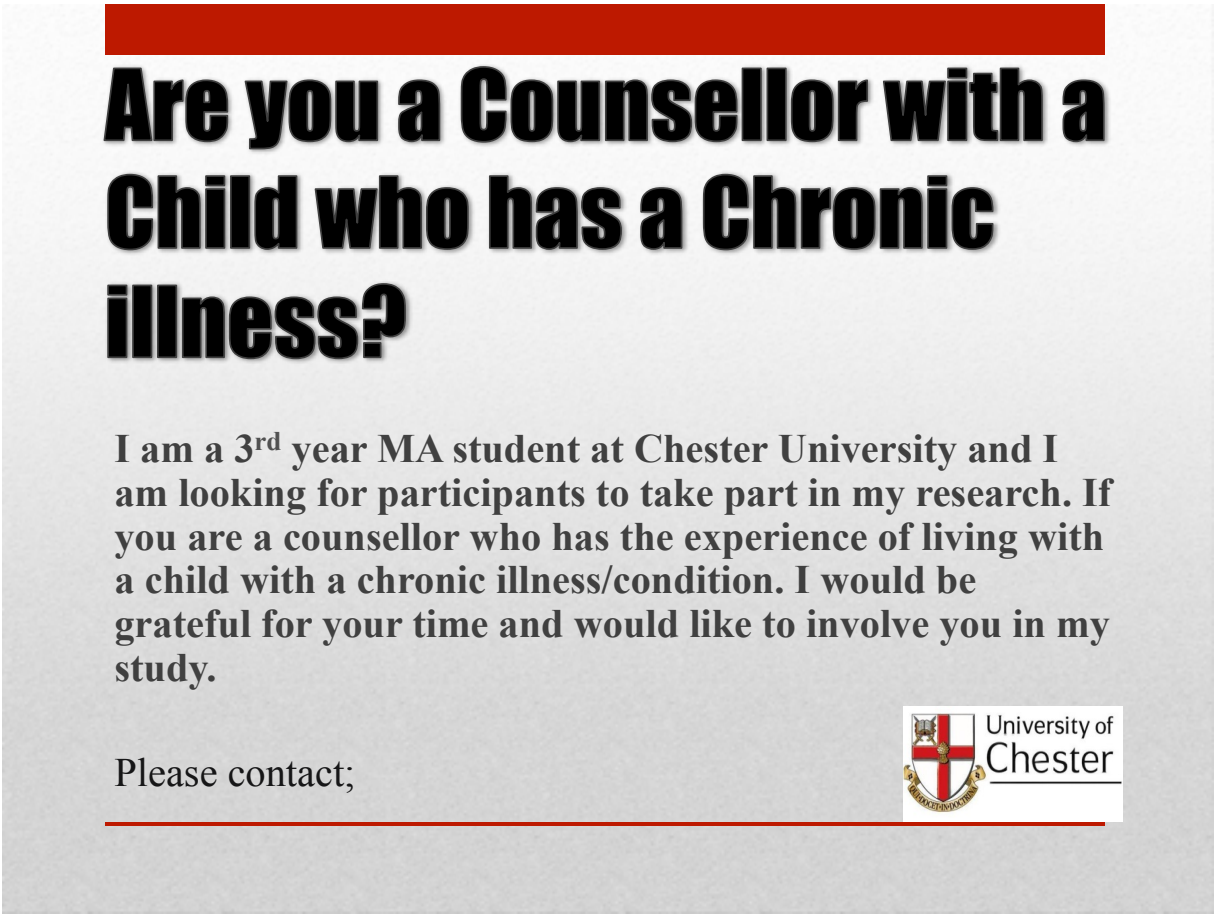
Spiritual/pastoral & public sectors

Counselling organisations

APPENDIX 3.


Counsellors who are Parents of a Child with a Life-Limiting, Chronic illness.
I am a 3rd year MA student at Chester University and I am looking for participants to take part in my research. If you are a counsellor who has the experience of living with a child with a life-limiting, chronic illness; 2 years have elapsed since your child's diagnosis and you are 2 years post qualified I would be grateful for your time and would like to involve you in my study.
Thank you.
Please contact;
University of Chester

APPENDIX 4.


Are you a Counsellor with a Child who has a Chronic illness?
I am a 3rd year MA student at Chester University and I am looking for participants to take part in my research. If you are a counsellor who has the experience of living with a child with a chronic illness/condition. I would be grateful for your time and would like to involve you in my study.
Please contact;
University of Chester

APPENDIX 5.

Dear Sir/Madam

Re: Masters Degree Research Study on 'Counsellors who are Parents of a Child with a Life Limiting, Chronic Illness'.

I am currently a student at the University of Chester studying for a Masters Degree in Clinical Counselling. As part of the degree I am required to undertake a dissertation. As the dissertation is an Interpretative phenomenological analysis of a counsellor's experience it necessitates my interviewing 4 to 6 counsellors for approximately 45 to 60 minutes.

I am writing to enquire if your organisation would consider displaying the enclosed poster inviting counsellors to participate in my research. Once they have contacted me I will send them an information sheet and an initial questionnaire for their suitability, before they are interviewed. University of Chester Ethics Committee has granted formal ethical approval for this study.

Thank you for taking the time to read this letter and I hope you can be of assistance in this sensitive topic of counselling research. Please do not hesitate to contact me if you require any further information.

Yours Sincerely

APPENDIX 6.

Dear Sir/Madam

Re: Masters Degree Research Study on 'Counsellors who are parents of a child with a chronic illness'.

I have sent you a similar poster just recently, but because I have had no response I have changed the title slightly to just 'chronic illness' for clarity.

I am writing to enquire if your organisation would consider displaying this poster and removing the other one, so I can invite counsellors to participate in this research study. Once they have contacted me I will send them an information sheet and an initial questionnaire for their suitability, before they are interviewed. University of Chester Ethics Committee has granted formal ethical approval for this study.

Just to reiterate. I am a student at the University of Chester studying for a Masters Degree in Clinical Counselling and as part of the degree I am required to undertake a dissertation. As the dissertation is an Interpretative phenomenological analysis of a counsellor's experience it necessitates my interviewing 4 to 6 counsellors for approximately 45 to 60 minutes.

Please do not hesitate to contact me if you require any further information.

Yours Sincerely

APPENDIX 7.

LETTER TO INCLUDE RESPONDENTS:

Re: Masters Degree Research Study

Thank you for expressing your interest to participate in this research study entitled *'*Counsellors' experience of living with a child with a chronic illness' which is part of a Masters Degree in Clinical Counselling Studies at the University of Chester.

Before you decide whether you would like to participate, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the information sheet carefully.

If you agree to participate in the study please complete and return the enclosed the *information sheet, Initial Questionnaire* and *Informed Consent* documents by post to the above address. The Questionnaire will help me select a maximum of six counsellors from a range of backgrounds and counselling environments to take part in a one to one interview. A summary of data from the completed questionnaires may be included in the final dissertation.

If you are selected to participate in a one to one interview I will contact you to arrange a suitable date, time and venue. You may withdraw from the research study at any time without obligation.

If you have any further queries about the study or any of the documents please do not hesitate to contact me.

APPENDIX 8.

UNIVERSITY OF CHESTER DEPARTMENT OF SOCIAL AND COMMUNICATION STUDIES

Masters Degree in Counselling Studies

RESEARCH QUESTIONNAIRE

Research Study Title: Counsellors' experience of living with a child with a chronic illness.

Name:……

Tel No. ……Email address: ……..…….

These questions are designed to elicit information to assess whether participants are suitable for this research project. This is not a judgment on any individual rather a matter of practicality; there are therefore no right or wrong answers.

How many years have you been qualified as a counsellor? .....

What counselling qualifications do you hold?.....

What was the diagnosis of your child's condition?.....

How old is your child with the life-limiting, chronic illness?…….....

How many years have elapsed since diagnosis?.....

Do you have access to a personal counsellor?.....

If No (I can provide a list if requested)

Thank you for completing this questionnaire.

APPENDIX 9.

UNIVERSITY OF CHESTER DEPARTMENT OF SOCIAL AND COMMUNICATION STUDIES

Masters Degree in Counselling Studies

INFORMED CONSENT

Research Study Title: Counsellors' experience of living with a child with a chronic illness.

(Please tick)

- o I have read and understand the information sheet about why the above named research is being done and what it will involve for me as a participant in the research.

- o I am willing to participate in the above named research project and understand that a summary of data from the completed questionnaire document may be included in the final dissertation. I understand that Counselling Tutors and the External Examiner for the purpose of assessment and moderation may see the questionnaire and I also understand that they are bound by the British Association for Counselling and Psychotherapy Ethical Framework for Good Practice in Counselling and Psychotherapy. I further understand that a copy of the dissertation will be held in the University of Chester and may be made available electronically.

- o I have access to supervision and personal therapy

- o I am a member of a professional body

I am willing to participate in a one to one interview with the researcher to discuss my experience of being a counsellor and I have experience of living with a child with a life-limiting, chronic illness.

Name: (*please print)*

Signed:

Date:

Thank you for completing this Informed Consent document.

APPENDIX 10.

UNIVERSITY OF CHESTER DEPARTMENT OF SOCIAL AND COMMUNICATION STUDIES.

M. A. in Clinical Counselling studies research consent form involving audio–taped recordings.

I .....hereby give my consent for the details of a written transcript based on an audio recorded interview with myself and Caroline Bodell to be submitted and used as part of my research dissertation for the M. A. in Clinical Counselling Studies at the University of Chester. I understand that my identity will remain anonymous and that all personally identifiable information will remain confidential and separate from the research data. I further understand that the Clinical Counselling Tutors and the External Examiner for the purpose of assessment and moderation may see the transcript. I also understand the ethics of this research will follow the British Association for Counselling and Psychotherapy Ethical Framework for Good Practice in Counselling and Psychotherapy.

I understand that I will be provided with a copy of the taped interview. I will also have access to the transcribed material should I so wish. I am aware that I can stop the interview at any point, or ultimately withdraw the interview within one month of my being provided with a copy of my audiotape. Upon completion of the research study the audiotape will be offered to me, or, by prior agreement with me, destroyed.

Excerpts from the transcript will be included in the dissertation and every effort will be made to ensure complete anonymity. Copies of the dissertation will be held in the University of Chester Library and the Department of Social and Communication Studies Resource Room. Without my further consent some or all of the material may

be used for publication and or presentation at conferences and seminars.

I have been provided with information about the nature of the research, including any possible risks, and have had a chance to check out any questions or concerns with the researcher, to give my informed consent to participate.

Signed (Participant).....Date.....

Signed (Researcher).....Date.....

APPENDIX 11.

Research Information Sheet

Title of dissertation: Counsellors' experience of living with a child with a chronic illness.

About me: I am a third year postgraduate student at Chester University studying for an MA in Clinical Counselling. My interest stems from being a parent of a child with a chronic illness. My placement also offers a counselling service to carers on the Wirral where I have had the opportunity to work with other parents who face the day-to-day difficulties of caring and living with a child with a chronic illness.

Aim: The purpose of this study is to explore counsellors' experience of being a parent of a child with a chronic illness. My key research questions will focus on the psychological impact during their child's illness, including diagnosis and/or prognosis and the social and cultural preconceptions and pressures.

Criteria for inclusion in the study include:

- You are 2 years post qualified to at least diploma level.
- You are a parent or guardian of a child with a chronic illness.
- 2 years have elapsed since diagnosis.
- You are in supervision and have access to a personal counsellor.
- You feel sufficiently robust to discuss the research topic.

What does participating in this research mean? If you choose to put yourself forward to participate and you meet the inclusion criteria, your involvement will be an hour-long, audio-recorded interview that will be held in a private room at Chester University or a mutually convenient, safe and confidential location. After the interview I will send you a copy of the transcript for you to check for accuracy and to ensure that it is a true account of your experience.

What are the potential risks? There is a risk that exploring this sensitive topic may bring up unexpected painful feelings for you. If this were the case, I hope that you would use the support of your supervisor or personal counsellor, and I will also ensure that you are given a list of BACP registered counsellors.

What are the potential benefits?

In carrying out the research, I hope to gain an understanding of the psychological impact that counsellors experience and hopefully identify what are the social and cultural preconceptions and pressures they feel, during their child's illness. I hope this will also make a valuable contribution to existing and future research.

Confidentiality: Throughout the research and writing up of my dissertation I will ensure that your anonymity is protected by allocating a pseudonym to all information relating to your involvement in the research. Any information or parts of the interview, which may identify you or your family, will not be included in the research. With your consent, verbatim sections of the interview may be used in the final dissertation. All information relating to the participants will remain confidential unless doing so may risk harm to themselves or others, or it would be breaking the law.

Can participants withdraw from the study?

My participants may withdraw from the research study at any time, up until the submission date without explanation or fear of reprisal.

What will happen to the results? The results of my research will form part of my Masters dissertation, which will be submitted to Chester University who will keep a hard copy, and a copy may also be available electronically. The results may also form part of other works, which are put forward for publication.

Data Protection: My data will consist of the audio recordings and transcriptions of interviews with my research participants. The interviews will be recorded onto a digital recorder, which will be kept securely when not in use. Recordings will be transferred onto my PC and their file will be password protected. Files will be saved under a pseudonym so that individuals may not be recognised from the file name. A back up copy of the files will be held on a memory stick, which will be kept in a locked drawer.

Is the research approved?

Yes, it has been approved by the Department of Social Studies and Counselling Ethics Committee and it will be conducted with full regard to the British Association for Counselling and Psychotherapy (2002), Ethical Framework for Good Practice in Counselling and Psychotherapy and the University's Research Governance Handbook in order to protect my participants from harm and to enhance the trustworthiness of my study.

Dr Valda Swinton at the University of Chester supervises my research. If you wish to complain or you perceive a problem with the research and this is not adequately resolved by communication with the researcher, my supervisor may be contacted.

Do you have any other queries?

If you feel you require any additional information or would like to query anything on this information sheet, I would be happy to discuss this in more detail.

Thank you for reading this information sheet.

APPENDIX 12.

Demographic table

Please complete;

Relationship of parent interviewed	
Childs age now?	
Medical condition/Diagnosis?	
What family members live at home?	
How long has it been since diagnosis?	
Do you have any religious belief? &/or a particular culture to note?	
Any other information that may help analysis &/or discussion?	

Thank you.

APPENDIX 13.

Questionnaire for participants

Self:

1. What impact did diagnosis have on you psychologically, if any?
2. What coping strategies did you or have you used? If any?
3. What factors have helped you cope better, if any?
4. Have you experienced any physical &/or debilitating symptoms?
5. Have any of your values or beliefs changed since diagnosis?
6. Have any pre-conceived ideas you held before diagnosis changed?
7. Have there been any major adjustments or changes to your life?

Support:

8. What has been the biggest support to you?
9. Who has been the biggest support to you?
10. Have you always felt understood & by whom?
11. Has your child's illness had an affect on any particular relationship/s?
12. What is or has been helpful at times of crisis?
13. Did they seek any therapeutic help with regards to your child's illness?

    If yes - was it before, during or after diagnosis?

    If no – why not and on reflection, do they think it would have helped?

APPENDIX 14.

Participants interviewed;

(Pseudonym) Name	**Victoria / V**	**Julia / J**	**Amy / A**	**Shelia / S**
Relationship to child	Mother / Son	Mother / Son	Mother / Daughter	Mother / Son
Childs age now?	24 Years old	27 Years old	16 Years old	5 years old
What family members live at home, in relation to child?	Mum, Step-Dad	Mum, Sister	Mum, Dad, Brother	Mum, Dad, Sister
How long has it been since diagnosis?	22 years	27 years	13 years	24 months
Do you have any religious belief? &/or a particular culture to note?	None	Roman Catholic	Christian	Church of Wales
Marital status	Divorced	Divorced	Married	Married
Age of child at diagnosis	2 ½ years	Birth	Aprox 5 years	Aprox 3 years old
Impact at birth	Unknown but had a fear something was wrong	Catatonic – couldn't talk for several days in hospital	Felt something wasn't right from 1 year old; told it was too soon to tell	Diagnosed when he was around 3 years old; didn't contemplate anything before this
Started counselling training	When son was 2 – 2 ½ but before divorce	Trained after diagnosis and after divorce	Trained after diagnosis but had always wanted to do counselling as a career progression	CBT counsellor before diagnosis

APPENDIX 15.

Master themes with super-ordinate themes below

Somatic	**Psychological**	**Behavioural**	**Cognitive**	**Personal Relations**
*Shock	Loss Fear Anxiety & Stress Helplessness Sadness & Hurt	*Positive *Control	Denial Disbelief & Confusion Psychological coping Preoccupation with child's illness	*Loneliness Emotional support
1	5	2	5	3

*Describes what context this represents.

Psychological variables;

Shock; as a stress reaction / stress response / predictable & unpredictable diagnosis.

Positive; using positivity to enhance the situation as a form of resilience.

Control; needing to compensate for not being able to control diagnosis or prognosis and used as a form of resilience.

Loneliness; feeling isolated and disconnected, through not feeling understood

APPENDIX 16.

	Super-ordinate themes;	Victoria	Julia	Amy	Shelia
1	Shock	2	2	2	2
2	Loss	2	2	2	1
3	Fear	1	3	1	2
4	Anxiety & Stress	3	-	1	-
5	Helplessness	1	3	-	1
6	Sadness & Hurt	2	1	1	2
7	Positive behaviour & Resilience	2	2	1	2
8	Taking control & Resilience	2	1	2	2
9	Denial	3	3	2	1
10	Disbelief	3	2	-	1
11	Psychological coping skills	1	1	-	1
12	Preoccupation with child's illness	3	1	6	3
13	Loneliness	2	2	-	1
14	Emotional support	1	1	3	1

Master themes; numbers show quotes used

Somatic 1

Psychological 2 - 6

Behavioural 7 – 8

Cognitive 9 - 12

Personal relations 13 - 14

APPENDIX 17.

Guidelines for Interpretative Phenomenological Analysis (IPA)

Each interview will need to be analysed separately.

Each interview will have its own list & table initially.

This is not meant to be prescriptive or exhaustive; there are many other ways of doing the initial noting.

1. Read the transcript a number of times and note down anything that strikes you as interesting or significant about what the respondent is saying. Some of these comments may be attempts at summarising, some may be associations or connections that come to mind, and others may be your preliminary interpretations.

2. On a separate sheet, using a table, document key words that capture the essential quality of what you are finding in the text, including what you have already noted.

3. In another column produce a list of themes that identify what the participants are saying and call this a emergent themes, also adding extracts from the main transcript and indicator line identifiers.

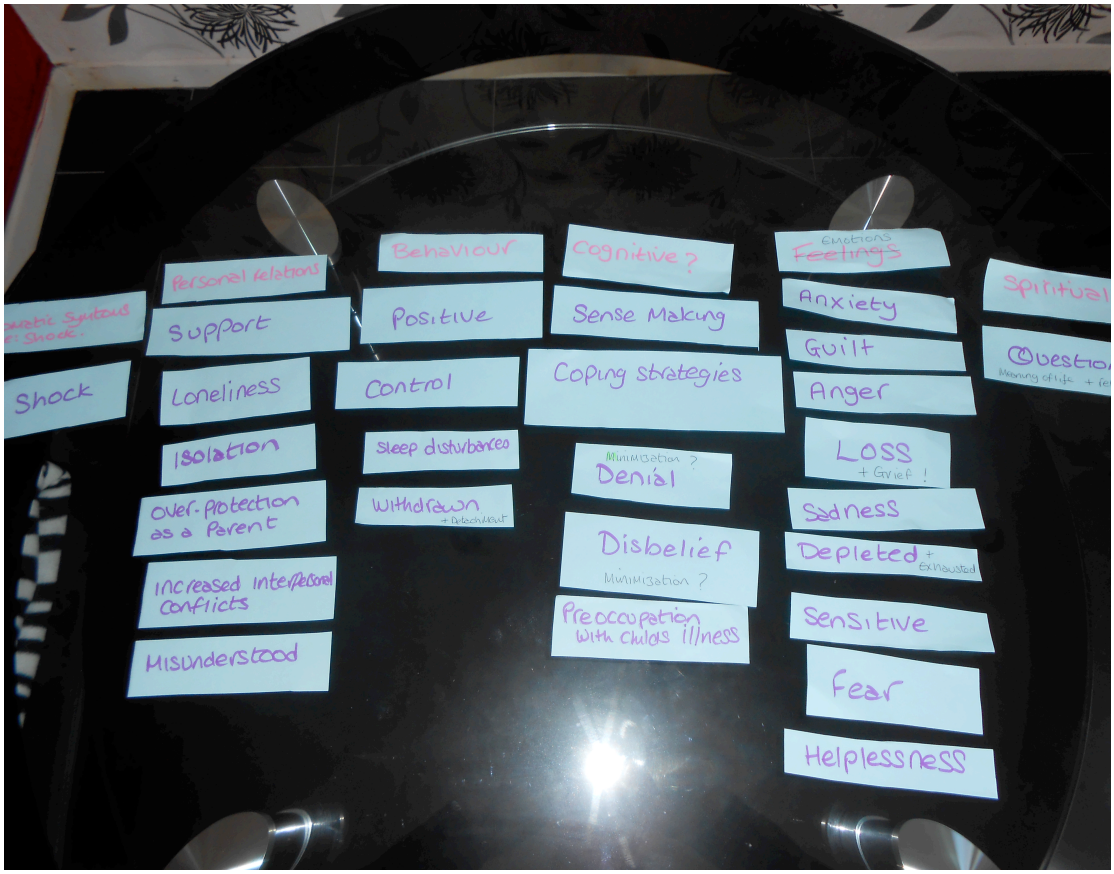
4. You may find that during this process you come up with a super-ordinate themes that helps to pull together a number of initial categories you had identified. As new clustering's of themes emerge, check back to the transcript to make sure the connections also work from the transcript and what the participant actually said. This form of analysis involves a close interaction between you and the text, attempting to understand what the person is saying but as part of the process, drawing on your own interpretative resources. This process may have also identified major themes that seem to capture most strongly the participant's experience.

6. The next stage is looking for patterns across the participant's experiences, looking for themes that are the most potent? Sometimes this may lead to a reconfiguring and

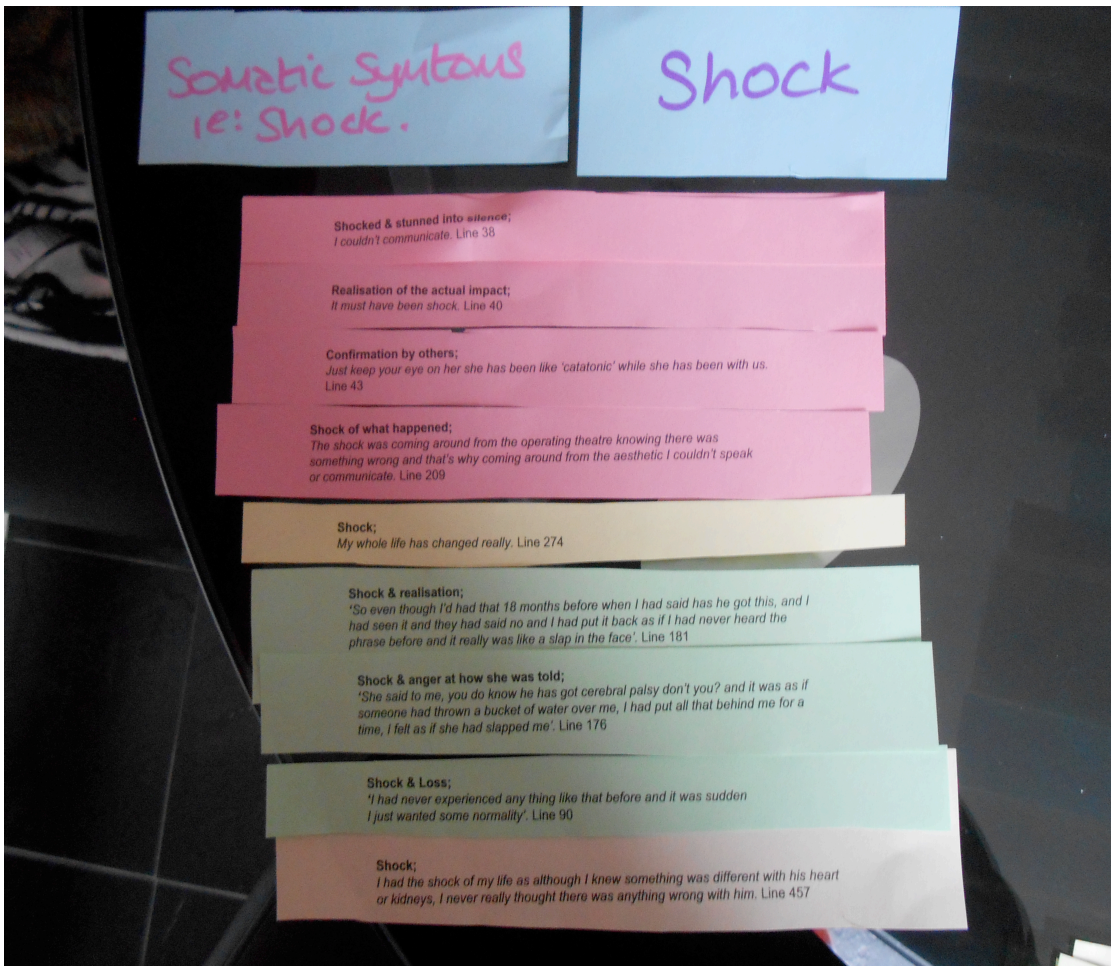
relabeling of the themes, and some of these will point to ways in which participant's unique idiosyncratic instances share higher order qualities that can be themed together to create a master theme. The final stage of analysis is to integrate themes across the data set as a whole. This process can be presented in a number of ways; most usually it has been in the form of a table that shows all the participants together, and the master themes are illustrated by nesting the super-ordinate themes under each title that has emerged, giving an example from each participant.

(Smith, Flowers & Larkin, 2010

APPENDIX 18.


Personal relations
Support
Loneliness
Isolation
over-protection as a Parent
Increased interpersonal conflicts
Misunderstood
Shock
Behaviour
Positive
Control
Sleep disturbances
Withdrawn
Cognitive ?
Sense Making
Coping strategies
Minimisation ?
Denial
Disbelief
Minimisation ?
Preoccupation with childs illness
Emotions
Feelings
Anxiety
Guilt
Anger
Loss + Grief !
Sadness
Depleted + Exhausted
Sensitive
Fear
Helplessness
Spiritual


Personal relations
Support
Loneliness
Isolation
Increased interpersonal conflicts
Misunderstood
Shock
Behaviour
Positive
Control
Cognitive ?
Sense Making
Coping strategies
Denial
Disbelief
Preoccupation with childs illness
Anxiety
Guilt
Anger
Loss + Grief !
Sadness
Depleted + Exhausted
Sensitive
Fear
Helplessness
Spiritual
Questioning
Therapy


Somatic Syntaxis
ie: Shock.
Shock
Shocked & stunned into silence;
I couldn't communicate. Line 38
Realisation of the actual impact;
It must have been shock. Line 40
Confirmation by others;
Just keep your eye on her she has been like 'catatonic' while she has been with us.
Line 43
Shock of what happened;
The shock was coming around from the operating theatre knowing there was
something wrong and that's why coming around from the aesthetic I couldn't speak
or communicate. Line 209
Shock;
My whole life has changed really. Line 274
Shock & realisation;
'So even though I'd had that 18 months before when I had said has he got this, and I
had seen it and they had said no and I had put it back as if I had never heard the
phrase before and it really was like a slap in the face'. Line 181
Shock & anger at how she was told;
'She said to me, you do know he has got cerebral palsy don't you? and it was as if
someone had thrown a bucket of water over me, I had put all that behind me for a
time, I felt as if she had slapped me'. Line 176
Shock & Loss;
'I had never experienced any thing like that before and it was sudden
I just wanted some normality'. Line 90
Shock;
I had the shock of my life as although I knew something was different with his heart
or kidneys, I never really thought there was anything wrong with him. Line 457